General

Guideline Title

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges.

Bibliographic Source(s)

National Collaborating Centre for Mental Health. Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. London (UK): National Institute for Health and Care Excellence (NICE); 2015 May 28. 57 p. (NICE guideline; no. 11).

Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Regulatory Alert

FDA Warning/Regulatory Alert

Note from the National Guideline Clearinghouse: This guideline references a drug(s) for which important revised regulatory and/or warning information has been released.

- May 10, 2016 – Olanzapine : The U.S. Food and Drug Administration (FDA) is warning that the antipsychotic medicine olanzapine can cause a rare but serious skin reaction that can progress to affect other parts of the body. FDA is adding a new warning to the drug labels for all olanzapine-containing products that describes this severe condition known as Drug Reaction with Eosinophilia and Systemic Symptoms (DRESS).

Recommendations

Major Recommendations

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Mental Health (NCCMH) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance.

The wording used in the recommendations in this guideline (for example, words such as 'offer' and 'consider') denotes the certainty with which the recommendation is made (the strength of the recommendation) and is defined at the end of the "Major Recommendations" field.

General Principles of Care

Working with People with a Learning Disability and Behaviour That Challenges, and Their Families and Carers

Work in partnership with children, young people and adults who have a learning disability and behaviour that challenges, and their family members or carers, and:

- Involve them in decisions about care
- Support self-management and encourage the person to be independent
- Build and maintain a continuing, trusting and non-judgemental relationship
- Provide information:
    - About the nature of the person's needs, and the range of interventions (for example, environmental, psychological and pharmacological interventions) and services available to them
    - In a format and language appropriate to the person's cognitive and developmental level (including spoken and picture formats, and written versions in Easy Read style and different colours and fonts)
- Develop a shared understanding about the function of the behaviour
- Help family members and carers to provide the level of support they feel able to

When providing support and interventions for people with a learning disability and behaviour that challenges, and their family members or carers:

- Take into account the severity of the person's learning disability, their developmental stage, and any communication difficulties or physical or mental health problems
- Aim to provide support and interventions:
    - In the least restrictive setting, such as the person's home, or as close to their home as possible, and
    - In other places where the person regularly spends time (for example, school or residential care)
- Aim to prevent, reduce or stop the development of future episodes of behaviour that challenges
- Aim to improve quality of life
- Offer support and interventions respectfully
- Ensure that the focus is on improving the person's support and increasing their skills rather than changing the person
- Ensure that they know who to contact if they are concerned about care or interventions, including the right to a second opinion
- Offer independent advocacy to the person and to their family members or carers

Understanding Learning Disabilities and Behaviour That Challenges

Everyone involved in commissioning or delivering support and interventions for people with a learning disability and behaviour that challenges (including family members and carers) should understand:

- The nature and development of learning disabilities
- Personal and environmental factors related to the development and maintenance of behaviour that challenges
- That behaviour that challenges often indicates an unmet need
- The effect of learning disabilities and behaviour that challenges on the person's personal, social, educational and occupational functioning
- The effect of the social and physical environment on learning disabilities and behaviour that challenges (and vice versa), including how staff and carer responses to the behaviour may maintain it

Delivering Effective Care

Health and social care provider organisations should ensure that teams carrying out assessments and delivering interventions recommended in this guideline have the training and supervision needed to ensure that they have the necessary skills and competencies.

If initial assessment (see "Assessment of Behaviour That Challenges" below) and management have not been effective, or the person has more complex needs, health and social care provider organisations should ensure that teams providing care have prompt and coordinated access to specialist assessment, support and intervention services. These services should provide advice, supervision and training from a range of staff to support the implementation of any care or intervention, including psychologists, psychiatrists, behavioural analysts, nurses, social care staff, speech and language therapists, educational staff, occupational therapists, physiotherapists, physicians, paediatricians and pharmacists.

Staff Training, Supervision and Support

Health and social care provider organisations should ensure that all staff working with people with a learning disability and behaviour that challenges are trained to deliver proactive strategies to reduce the risk of behaviour that challenges, including:

- Developing personalised daily activities
- Adapting a person's environment and routine
- Strategies to help the person develop an alternative behaviour to achieve the same purpose by developing a new skill (for example, improved communication, emotional regulation or social interaction)
- The importance of including people, and their family members or carers, in planning support and interventions
- Strategies designed to calm and divert the person if they show early signs of distress
- Delivering reactive strategies

Health and social care provider organisations should ensure that all staff get personal and emotional support to:

- Enable them to deliver interventions effectively for people with a learning disability and behaviour that challenges
- Feel able to seek help for difficulties arising from working with people with a learning disability and behaviour that challenges
- Recognise and manage their own stress

Health and social care provider organisations should ensure that all interventions for behaviour that challenges are delivered by competent staff. Staff should:

- Receive regular high-quality supervision that takes into account the impact of individual, social and environmental factors
- Deliver interventions based on the relevant treatment manuals
- Consider using routine outcome measures at each contact (for example, the Adaptive Behavior Scale and the Aberrant Behavior Checklist)
- Take part in monitoring (for example, by using Periodic Service Review methods)
- Evaluate adherence to interventions and practitioner competence (for example, by using video and audio recording, and external audit and scrutiny)

Organising Effective Care

The recommendations in this section are adapted from the NICE guideline on common mental health disorders. (See the NGC summary of the NICE guideline Common mental health disorders. Identification and pathways to care [NICE clinical guideline 123].)

A designated leadership team of healthcare professionals, educational staff, social care practitioners, managers and health and local authority commissioners should develop care pathways for people with a learning disability and behaviour that challenges for the effective delivery of care and the transition between and within services that are:

- Negotiable, workable and understandable for people with a learning disability and behaviour that challenges, their family members or carers, and staff
- Accessible and acceptable to people using the services, and responsive to their needs
- Integrated (to avoid barriers to movement between different parts of the care pathways)
- Focused on outcomes (including measures of quality, service-user experience and harm)

The designated leadership team should be responsible for developing, managing and evaluating care pathways, including:

- Developing clear policies and protocols for care pathway operation
- Providing training and support on care pathway operation
- Auditing and reviewing care pathway performance

The designated leadership team should work together to design care pathways that promote a range of evidence-based interventions and support people in their choice of interventions.

The designated leadership team should work together to design care pathways that respond promptly and effectively to the changing needs of the people they serve and have:

- Clear and agreed goals for the services offered
- Robust and effective ways to measure and evaluate the outcomes associated with the agreed goals

The designated leadership team should work together to design care pathways that provide an integrated programme of care across all care services and:

- Minimise the need for transition between different services or providers
- Provide the least restrictive alternatives for people with behaviour that challenges
- Allow services to be built around the care pathway (and not the other way around)
- Establish clear links (including access and entry points) to other care pathways (including those for physical healthcare needs)
- Have designated staff who are responsible for coordinating people's engagement with a care pathway and transition between services within and between care pathways

The designated leadership team should work together to ensure effective communication about the functioning of care pathways. There should be protocols for sharing information:

- With people with a learning disability and behaviour that challenges, and their family members or carers (if appropriate), about their care
- About a person's care with other staff (including general practitioners [GPs])
- With all the services provided in the care pathway
- With services outside the care pathway

Physical Healthcare

GPs should offer an annual physical health check to children, young people and adults with a learning disability in all settings, using a standardised template (such as the Cardiff health check template). See the Royal College of General Practitioners' guide for GP practices on annual health checks for people with a learning disability for further information. This should be carried out together with a family member, carer or healthcare professional or social care practitioner who knows the person and include:

- A review of any known or emerging behaviour that challenges and how it may be linked to any physical health problems
- A physical health review
- A review of all current health interventions, including medication and related side effects, adverse events, drug interactions and adherence
- An agreed and shared care plan for managing any physical health problems (including pain)

Support and Interventions for Family Members or Carers

Involve family members or carers in developing and delivering the support and intervention plan for children, young people and adults with a learning disability and behaviour that challenges. Give them information about support and interventions in a format and language that is easy to understand, including NICE's 'Information for the public' (see the "Patient Resources" field).

Advise family members or carers about their right to, and explain how to get:

- A formal carer's assessment of their own needs (including their physical and mental health)
- Short breaks and other respite care

When providing support to family members or carers (including siblings):

- Recognise the impact of living with or caring for a person with a learning disability and behaviour that challenges
- Explain how to access family advocacy
- Consider family support and information groups if there is a risk of behaviour that challenges, or it is emerging
- Consider formal support through disability-specific support groups for family members or carers and regular assessment of the extent and severity of the behaviour that challenges
- Provide skills training and emotional support, or information about these, to help them take part in and support interventions for the person with a learning disability and behaviour that challenges

If a family member or carer has an identified mental health problem, consider:

- Interventions in line with existing NICE guidelines or
- Referral to a mental health professional who can provide interventions in line with existing NICE guidelines

Early Identification of the Emergence of Behaviour That Challenges

Everyone involved in caring for and supporting children, young people and adults with a learning disability (including family members and carers) should understand the risk of behaviour that challenges and that it often develops gradually. Pay attention to and record factors that may increase this risk, including:

- Personal factors, such as:

    - A severe learning disability
    - Autism
    - Dementia
    - Communication difficulties (expressive and receptive)
    - Visual impairment (which may lead to increased self-injury and stereotypy)
    - Physical health problems
    - Variations with age (peaking in the teens and twenties)
- Environmental factors, such as:
    - Abusive or restrictive social environments
    - Environments with little or too much sensory stimulation and those with low engagement levels (for example, little interaction with staff)
    - Developmentally inappropriate environments (for example, a curriculum that makes too many demands on a child or young person)
    - Environments where disrespectful social relationships and poor communication are typical or where staff do not have the capacity or resources to respond to people's needs
    - Changes to the person's environment (for example, significant staff changes or moving to a new care setting)

Consider using direct observation and recording or formal rating scales (for example, the Adaptive Behavior Scale or Aberrant Behavior Checklist) to monitor the development of behaviour that challenges.

Assessment of Behaviour That Challenges

The Assessment Process

When assessing behaviour that challenges shown by children, young people and adults with a learning disability follow a phased approach, aiming to gain a functional understanding of why the behaviour occurs. Start with initial assessment and move on to further assessment if, for example, intervention has not been effective or the function of the behaviour is not clear. Develop a behaviour support plan (see recommendation below) as soon as possible.

When assessing behaviour that challenges ensure that:

- The person being assessed remains at the centre of concern and is supported throughout the process
- The person and their family members and carers are fully involved in the assessment process
- The complexity and duration of the assessment process is proportionate to the severity, impact, frequency and duration of the behaviour
- Everyone involved in delivering assessments understands the criteria for moving to more complex and intensive assessment (see recommendation below)
- All current and past personal and environmental factors (including care and educational settings) that may lead to behaviour that challenges are taken into account
- Assessment is a flexible and continuing (rather than a fixed) process, because factors that trigger and maintain behaviour may change over time
- Assessments are reviewed after any significant change in behaviour
- Assessments are focused on the outcomes of reducing behaviour that challenges and improving quality of life
- The resilience, resources and skills of family members and carers are taken into account
- The capacity, sustainability and commitment of the staff delivering the behaviour support plan are taken into account

Explain to the person and their family members or carers how they will be told about the outcome of any assessment of behaviour that challenges. Ensure that feedback is personalised and involves a family member, carer or advocate to support the person and help them to understand the feedback if needed.

Initial Assessment of Behaviour That Challenges

If behaviour that challenges is emerging or apparent, or a family member, carer or member of staff (such as a teacher or care worker), has concerns about behaviour, carry out initial assessment that includes:

- A description of the behaviour (including its severity, frequency, duration and impact on the person and others) from the person (if possible) and a family member, carer or a member of staff (such as a teacher or care worker)
- An explanation of the personal and environmental factors involved in developing or maintaining the behaviour from the person (if possible) and a family member, carer or a member of staff (such as a teacher or care worker)
- The role of the service, staff, family members or carers in developing or maintaining the behaviour

Consider using a formal rating scale (for example, the Aberrant Behavior Checklist or Adaptive Behavior Scale) to provide baseline levels for the behaviour and a scale (such as the Functional Analysis Screening Tool) to help understand its function.

As part of initial assessment of behaviour that challenges, take into account:

- The person's abilities and needs (in particular, their expressive communication and receptive communication)
- Any physical or mental health problems, and the effect of medication, including side effects
- Developmental history, including neurodevelopmental problems (including the severity of the learning disability and the presence of autism or other behavioural phenotypes)
- Response to any previous interventions for behaviour that challenges
- The impact of the behaviour that challenges on the person's:
    - Quality of life and that of their family members or carers
    - Independent living skills and educational or occupational abilities
- Social and interpersonal history, including relationships with family members, carers, staff (such as teachers) or other people with a learning disability (such as those the person lives with)
- Aspects of the person's culture that could be relevant to the behaviour that challenges
- Life history, including any history of trauma or abuse
- Recent life events and changes to routine
- The person's sensory profile, preferences and needs
- The physical environment, including heat, light, noise and smell
- The care environment, including the range of activities available, how it engages people and promotes choice, and how well structured it is

After initial assessment, develop a written statement (formulation) that sets out an understanding of what has led to the behaviour that challenges and the function of the behaviour. Use this to develop a behaviour support plan (see recommendation below).

Risk Assessment

Assess and regularly review the following areas of risk during any assessment of behaviour that challenges:

- Suicidal ideation, self-harm (in particular in people with depression) and self-injury
- Harm to others
- Self-neglect
- Breakdown of family or residential support
- Exploitation, abuse or neglect by others
- Rapid escalation of the behaviour that challenges

Ensure that the behaviour support plan includes risk management (see recommendation below).

Further Assessment of Behaviour That Challenges

If the behaviour that challenges is severe or complex, or does not respond to the behaviour support plan, review the plan and carry out further assessment that is multidisciplinary and draws on skills from specialist services, covering any areas not fully explored by initial assessment. Carry out a functional assessment, identifying and evaluating any factors that may provoke or maintain the behaviour (see recommendations below). Consider using formal (for example, the Adaptive Behavior Scale or the Aberrant Behavior Checklist) and idiographic (personalised) measures to assess the severity of the behaviour and the progress of any intervention.

Functional Assessment of Behaviour

Carry out a functional assessment of the behaviour that challenges to help inform decisions about interventions. This should include:

- A clear description of the behaviour, including classes or sequences of behaviours that typically occur together
- Identifying the events, times and situations that predict when the behaviour will and will not occur across the full range of the person's daily routines and usual environments
- Identifying the consequences (or reinforcers) that maintain the behaviour (that is, the function or purpose that the behaviour serves)
- Developing summary statements or hypotheses that describe the relationships between personal and environmental triggers, the behaviour and its reinforcers
- Collecting direct observational data to inform the summary statements or hypotheses

Include the following in a functional assessment:

- A baseline measurement of current behaviour, and its frequency and intensity, and repeated measurements in order to evaluate change
- Measurements including direct observations and scales such as the Aberrant Behavior Checklist and self-reporting
- A baseline measurement of quality of life (such as the Life Experiences Checklist and the Quality of Life Questionnaire)
- Assessment of the impact of current or past interventions, including reactive strategies

Vary the complexity and intensity of the functional assessment according to the complexity and intensity of behaviour that challenges, following a phased approach as set out below.

- Carry out pre-assessment data gathering to help shape the focus and level of the assessment.
- For recent-onset behaviour that challenges, consider brief structured assessments such as the Functional Analysis Screening Tool or Motivation Assessment Scale to identify relationships between the behaviour and what triggers and reinforces it.
- For recent-onset behaviour that challenges, or marked changes in patterns of existing behaviours, take into account whether any significant alterations to the person's environment and physical or psychological health are associated with the development or maintenance of the behaviour.
- Consider in-depth assessment involving interviews with family members, carers and others, direct observations, structured record keeping, questionnaires and reviews of case records.
- If a mental health problem may underlie behaviour that challenges, consider initial screening using assessment scales such as the Diagnostic Assessment Schedule for the Severely Handicapped-II, Psychiatric Assessment Schedule for Adults with a Developmental Disability or the Psychopathology Instrument for Mentally Retarded Adults and seek expert opinion.

After Further Assessment

After further assessment, re-evaluate the written statement (formulation) and adjust the behaviour support plan if necessary.

Behaviour Support Plan

Develop a written behaviour support plan for children, young people and adults with a learning disability and behaviour that challenges that is based on a shared understanding about the function of the behaviour. This should:

- Identify proactive strategies designed to improve the person's quality of life and remove the conditions likely to promote behaviour that challenges, including:
    - Changing the environment (for example, reducing noise, increasing predictability)
    - Promoting active engagement through structured and personalised daily activities, including adjusting the school curriculum for children and young people
- Identify adaptations to a person's environment and routine, and strategies to help them develop an alternative behaviour to achieve the function of the behaviour that challenges by developing a new skill (for example, improved communication, emotional regulation or social interaction)
- Identify preventive strategies to calm the person when they begin to show early signs of distress, including:
    - Individual relaxation techniques
    - Distraction and diversion onto activities they find enjoyable and rewarding
- Identify reactive strategies to manage any behaviours that are not preventable (see "Reactive Strategies" section below), including how family members, carers or staff should respond if a person's agitation escalates and there is a significant risk of harm to them or others
- Incorporate risk management and take into account the effect of the behaviour support plan on the level of risk
- Be compatible with the abilities and resources of the person's family members, carers or staff, including managing risk, and can be implemented within these resources
- Be supported by data that measure the accurate implementation of the plan
- Be monitored using the continuous collection of objective outcome data
- Be reviewed frequently (fortnightly for the first 2 months and monthly thereafter), particularly if behaviour that challenges or use of restrictive interventions increases, or quality of life decreases
- Identify any training for family members, carers or staff to improve their understanding of behaviour that challenges shown by people with a learning disability
- Identify those responsible for delivering the plan and the designated person responsible for coordinating it

Psychological and Environmental Interventions

Early Intervention for Children and Their Parents or Carers

Consider parent-training programmes for parents or carers of children with a learning disability who are aged under 12 years with emerging, or at

risk of developing, behaviour that challenges.

Parent-training programmes should:

- Be delivered in groups of 10 to 15 parents or carers
- Be accessible (for example, take place outside normal working hours or in community-based settings with childcare facilities)
- Focus on developing communication and social functioning
- Typically consist of 8 to 12 sessions lasting 90 minutes
- Follow the relevant treatment manual
- Employ materials to ensure consistent implementation of the programme

Consider preschool classroom-based interventions for children aged 3 to 5 years with emerging, or at risk of developing, behaviour that challenges.

Preschool classroom-based interventions should have multiple components, including:

- Curriculum design and development
- Social and communication skills training for the children
- Skills training in behavioural strategies for parents or carers
- Training on how to mediate the intervention for preschool teachers

Interventions for Behaviour That Challenges

Consider personalised interventions for children, young people and adults that are based on behavioural principles and a functional assessment of behaviour, tailored to the range of settings in which they spend time, and consist of:

- Clear targeted behaviours with agreed outcomes
- Assessment and modification of environmental factors that could trigger or maintain the behaviour (for example, altering task demands for avoidant behaviours)
- Addressing staff and family member or carer responses to behaviour that challenges
- A clear schedule of reinforcement of desired behaviour and the capacity to offer reinforcement promptly
- A specified timescale to meet intervention goals (modifying intervention strategies that do not lead to change within a specified time)

Consider individual psychological interventions for adults with an anger management problem. These interventions should be based on cognitive-behavioural principles and delivered individually or in groups over 15 to 20 hours.

Do not offer sensory interventions (for example, Snoezelen rooms) before carrying out a functional assessment to establish the person's sensory profile. Bear in mind that the sensory profile may change.

Consider developing and maintaining a structured plan of daytime activity (as part of the curriculum if the person is at school) that reflects the person's interests and capacity. Monitor the effects on behaviour that challenges and adjust the plan in discussion with the person and their family members or carers.

Medication

Consider medication, or optimise existing medication (in line with the NGC summary of the NICE guideline Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes [NICE guideline 5]), for coexisting mental or physical health problems identified as a factor in the development and maintenance of behaviour that challenges shown by children, young people and adults with a learning disability (see also recommendation under "Interventions for Coexisting Health Problems" below).

Consider antipsychotic medication to manage behaviour that challenges only if:

- Psychological or other interventions alone do not produce change within an agreed time or
- Treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or
- The risk to the person or others is very severe (for example, because of violence, aggression or self-injury)

Only offer antipsychotic medication in combination with psychological or other interventions.

When choosing which antipsychotic medication to offer, take into account the person's preference (or that of their family member or carer, if appropriate), side effects, response to previous antipsychotic medication and interactions with other medication.

Antipsychotic medication should initially be prescribed and monitored by a specialist (an adult or child psychiatrist or a neurodevelopmental paediatrician) who should:

- Identify the target behaviour
- Decide on a measure to monitor effectiveness (for example, direct observations, the Aberrant Behavior Checklist or the Adaptive Behavior Scale), including frequency and severity of the behaviour and impact on functioning
- Start with a low dose and use the minimum effective dose needed
- Only prescribe a single drug
- Monitor side effects as recommended, see the NGC summaries of the NICE guidelines Psychosis and schizophrenia in adults: treatment and management (NICE clinical guideline 178) and Psychosis and schizophrenia in children and young people: recognition and management (NICE clinical guideline 155)
- Review the effectiveness and any side effects of the medication after 3 to 4 weeks
- Stop the medication if there is no indication of a response at 6 weeks, reassess the behaviour that challenges and consider further psychological or environmental interventions
- Only prescribe p.r.n. (as-needed) medication for as short a time as possible and ensure that its use is recorded and reviewed
- Review the medication if there are changes to the person's environment (for example, significant staff changes or moving to a new care setting) or their physical or mental health

Ensure that the following are documented:

- A rationale for medication (explained to the person with a learning disability and everyone involved in their care, including their family members and carers)
- How long the medication should be taken for
- A strategy for reviewing the prescription and stopping the medication

If there is a positive response to antipsychotic medication:

- Record the extent of the response, how the behaviour has changed and any side effects or adverse events
- Conduct a full multidisciplinary review after 3 months and then at least every 6 months covering all prescribed medication (including effectiveness, side effects and plans for stopping)
- Only continue to prescribe medication that has proven benefit

When prescribing is transferred to primary or community care, or between services, the specialist should give clear guidance to the practitioner responsible for continued prescribing about:

- Which behaviours to target
- Monitoring of beneficial and side effects
- Taking the lowest effective dose
- How long the medication should be taken for
- Plans for stopping the medication

For the use of rapid tranquillisation, follow the NGC summary of the NICE guideline Violence and aggression: short-term management in mental health, health and community settings (NICE guideline 10).

Reactive Strategies

Only use reactive strategies for children, young people and adults with a learning disability and behaviour that challenges as a last resort and together with the proactive interventions described in the "Psychological and Environmental Interventions" section above. When risks to the person with a learning disability or others are significant, or breakdown in their living arrangements is very likely, consider using reactive strategies as an initial intervention and introduce proactive interventions once the situation stabilises.

Ensure that reactive strategies, whether planned or unplanned, are delivered on an ethically sound basis. Use a graded approach that considers the least restrictive alternatives first. Encourage the person and their family members or carers to be involved in planning and reviewing reactive strategies whenever possible.

If a restrictive intervention is used as part of a reactive strategy, follow the NGC summary of the NICE guideline Violence and aggression: short-term management in mental health, health and community settings (NICE guideline 10) for the safe use of restrictive interventions and carry out a thorough risk assessment. Take into account:

- Any physical health problems and physiological contraindications to the use of restrictive interventions, in particular manual and mechanical restraint
- Any psychological risks associated with the intervention, such as a history of abuse
- Any known biomechanical risks, such as musculoskeletal risks
- Any sensory sensitivities, such as a high or low threshold for touch

Document and review the delivery and outcome of the restrictive intervention and discuss these with everyone involved in the care of the person, including their family members and carers, and with the person if possible.

Ensure that any restrictive intervention is accompanied by a restrictive intervention reduction programme, as part of the long-term behaviour support plan, to reduce the use of and need for restrictive interventions.

Ensure that planned restrictive interventions:

- Take place within the appropriate legal framework of the Human Rights Act 1998, the relevant rights in the European Convention on Human Rights, the Mental Health Act 1983 and the Mental Capacity Act 2005, including the supplementary code of practice on deprivation of liberty safeguards
- Are in the best interest of the person to protect them or others from immediate and significant harm
- Are a reasonable, necessary and proportionate response to the risk presented

Regularly review and reassess the safety, efficacy, frequency of use, duration and continued need for reactive strategies, including restrictive interventions (follow the NGC summary of the NICE guideline Violence and aggression: short-term management in mental health, health and community settings [NICE guideline 10]. Document their use as part of an incident record and use this in personal and organisational debrief procedures to inform future behaviour support planning and organisational learning.

Interventions for Coexisting Health Problems

Offer children, young people and adults with a learning disability and behaviour that challenges interventions for any suspected or coexisting mental or physical health problems in line with the relevant NICE guideline for that condition (see also "Medication" section above). Adjust the nature, content and delivery of the interventions to take into account the impact of the person's learning disability and behaviour that challenges.

Interventions for Sleep Problems

Consider behavioural interventions for sleep problems in children, young people and adults with a learning disability and behaviour that challenges that consist of:

- A functional analysis of the problem sleep behaviour to inform the intervention (for example, not reinforcing non-sleep behaviours)
- Structured bedtime routines

Do not offer medication to aid sleep unless the sleep problem persists after a behavioural intervention, and then only:

- After consultation with a psychiatrist (or a specialist paediatrician for a child or young person) with expertise in its use in people with a learning disability
- Together with non-pharmacological interventions and regular reviews (to evaluate continuing need and ensure that the benefits continue to outweigh the risks)

If medication is needed to aid sleep, consider melatonin. (At the time of publication [May 2015], melatonin did not have a UK marketing authorisation for use in people aged under 55 years for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.)

Definitions

Strength of Recommendations

Some recommendations can be made with more certainty than others. The Guideline Development Group (GDG) makes a recommendation based on the trade-off between the benefits and harms of an intervention, taking into account the quality of the underpinning evidence. For some interventions, the GDG is confident that, given the information it has looked at, most people would choose the intervention. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the strength of the recommendation).

Interventions That Must (or Must Not) Be Used

The GDG usually uses 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally 'must' (or 'must not') is used if the consequences of not following the recommendation could be extremely serious or potentially life threatening.

Interventions That Should (or Should Not) Be Used – a 'Strong' Recommendation

The GDG uses 'offer' (and similar words such as 'refer' or 'advise') when confident that, for the vast majority of people, an intervention will do more good than harm, and be cost effective. The GDG uses similar forms of words (for example, 'Do not offer…') when they are confident that an intervention will not be of benefit for most people.

Interventions That Could Be Used

The GDG uses 'consider' when confident that an intervention will do more good than harm for most people, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to have the intervention at all, is more likely to depend on the person's values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the person.

Clinical Algorithm(s)

A National Institute for Health and Care Excellence (NICE) care pathway titled "Challenging Behaviour and Learning Disabilities Overview" is available from the NICE Web site .

Scope

Disease/Condition(s)

- Learning disabilities
- Challenging behaviour (behaviour that challenges)

Guideline Category

Counseling

Diagnosis

Evaluation

Management

Prevention

Risk Assessment

Screening

Treatment

Clinical Specialty

Family Practice

Internal Medicine

Neurology

Nursing

Pediatrics

Psychiatry

Psychology

Speech-Language Pathology

Intended Users

Advanced Practice Nurses

Health Care Providers

Nurses

Occupational Therapists

Patients

Physician Assistants

Physicians

Psychologists/Non-physician Behavioral Health Clinicians

Social Workers

Speech-Language Pathologists

Guideline Objective(s)

- To advise on the management and support of people with a learning disability and behaviour that challenges, and prevention of behaviour and challenges
- To make recommendations for the management and support of children, young people and adults with a learning disability and behaviour that challenges to:
    - Improve access and engagement with treatment and services for people with a learning disability and behaviour that challenges
    - Improve the methods of assessment and identification of those at risk of developing challenging behaviour
    - Evaluate the role of specific psychological, psychosocial, environmental and pharmacological interventions
    - Integrate the above to provide best-practice advice on the care of individuals
    - Promote the implementation of best clinical practice through the development of recommendations tailored to the requirements of the National Health Service (NHS) in England

Target Population

Children, young people and adults with mild, moderate, severe or profound learning disabilities and behaviour that challenges, and their families and carers

Interventions and Practices Considered

1. General principles of care
    - Working with people with a learning disability and behaviour that challenges, and their families and carers
    - Understanding learning disabilities and behaviour that challenges
    - Delivering effective healthcare
    - Staff training, supervision, and support

    - Organising effective care
2. Physical healthcare (e.g., annual physical exam, shared plan for managing physical health problems)
3. Support and interventions for family members or carers
4. Early identification of the emergence of behaviour that challenges
5. Assessment of behaviour that challenges
    - Assessment process
    - Initial assessment of behaviour that challenge (use of formal rating scales)
    - Risk assessment
    - Further assessment of severe or complex behaviour
    - Functional assessment of behaviour
6. Behaviour support plan
7. Psychological and environmental interventions
    - Early intervention for children and their parents or carers
    - Personalised, targeted psychological interventions
8. Medications, including antipsychotic medication
9. Reactive strategies
10. Interventions for coexisting health problems
11. Interventions for sleep problems (behavioural interventions and medications)

Major Outcomes Considered

- Severity, frequency and duration of the targeted behaviour that challenges
- Adaptive functioning, including communication skills
- Mental and psychological health outcomes (such as mood and anxiety)
- Quality of life
- Service user and carer satisfaction
- Effects on carer stress and resilience
- Adverse effects on other people with learning disabilities
- Rates of seclusion
- Rates of manual restraint
- Use of psychoactive medication
- Premature death
- Rates of placement breakdown
- Use of inpatient placements (including out-of-area placements)
- Cost-effectiveness of interventions

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Searches of Unpublished Data

Description of Methods Used to Collect/Select the Evidence

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Mental Health (NCCMH) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for

the full version of this guidance.

Clinical Review Methods

The Search Process

Scoping Searches

A broad preliminary search of the literature was undertaken in April 2013 to obtain an overview of the issues likely to be covered by the scope, and to help define key areas. The searches were restricted to clinical guidelines, Health Technology Assessment (HTA) reports, key systematic reviews and randomised controlled trials (RCTs). A list of databases and websites searched can be found in Appendix H in the full guideline appendices (see the "Availability of Companion Documents" field).

Systematic Literature Searches

After the scope was finalised, a systematic search strategy was developed to locate as much relevant evidence as possible. The balance between sensitivity (the power to identify all studies on a particular topic) and specificity (the ability to exclude irrelevant studies from the results) was carefully considered, and a decision made to utilise a broad approach to searching to maximise retrieval of evidence to all parts of the guideline. Searches were restricted to certain study designs if specified in the review protocol, and conducted in the following databases:

- Applied Social Sciences Index and Abstracts
- Australian Education Index
- British Education Index
- Cumulative Index to Nursing and Allied Health Literature (CINAHL)
- Cochrane Database of Abstracts of Reviews of Effects
- Cochrane Database of Systematic Reviews
- Cochrane Central Register of Controlled Trials
- Education Resources Information Center (ERIC)
- EMBASE (Excerpta Medica Database)
- HTA database (technology assessments)
- International Bibliography of the Social Sciences
- Medical Literature Analysis and Retrieval System Online (MEDLINE)/MEDLINE In-Process
- Psychological Information Database (PsycINFO)
- Sociological Abstracts
- Social Services Abstracts
- Social Sciences Citation Index

The search strategies were initially developed for MEDLINE before being translated for use in other databases/interfaces. Strategies were built up through a number of trial searches and discussions of the results of the searches with the review team and the Guideline Development Group (GDG) to ensure that all possible relevant search terms were covered. To ensure comprehensive coverage, search terms for learning disabilities and behaviour that challenges were kept purposely broad to help counter dissimilarities in database indexing practices and thesaurus terms, and imprecise reporting of study populations by authors in the titles and abstracts of records. The search terms for each search are set out in full in Appendix H in the full guideline appendices.

Reference Management

Citations from each search were downloaded into reference management software and duplicates removed. Records were then screened against the eligibility criteria of the reviews before being appraised for methodological quality. The unfiltered search results were saved and retained for future potential re-analysis to help keep the process both replicable and transparent.

Search Filters

To aid retrieval of relevant and sound studies, filters were used to limit a number of searches to systematic reviews, RCTs and qualitative studies. The search filters for systematic reviews and RCTs are adaptations of validated filters designed by the Health Information Research Unit at McMaster University. The qualitative research filter was developed in-house. Each filter comprises index terms relating to the study type(s) and associated text words for the methodological description of the design(s).

Date and Language Restrictions

Systematic database searches were initially conducted in August 2013 up to the most recent searchable date. Search updates were generated on a 6-monthly basis, with the final re-runs carried out in October 2014 ahead of the guideline consultation. After this point, studies were only included if they were judged by the GDG to be exceptional (for example, if the evidence was likely to change a recommendation).

Although no language restrictions were applied at the searching stage, foreign language papers were not requested or reviewed, unless they were of particular importance to a review question.

Date restrictions were not applied, except for searches of systematic reviews which were limited to research published from 1999. The search for systematic reviews was restricted to the last 15 years as older reviews were thought to be less useful.

Other Search Methods

Other search methods involved: (a) scanning the reference lists of all eligible publications (systematic reviews, stakeholder evidence and included studies) for more published reports and citations of unpublished research; (b) sending lists of studies meeting the inclusion criteria to subject experts (identified through searches and the GDG) and asking them to check the lists for completeness, and to provide information of any published or unpublished research for consideration (see Appendix E in the full guideline appendices); (c) checking the tables of contents of key journals for studies that might have been missed by the database and reference list searches; (d) tracking key papers in the Science Citation Index (prospectively) over time for further useful references; (e) conducting searches in ClinicalTrials.gov for unpublished trial reports; (f) contacting included study authors for unpublished or incomplete datasets. Searches conducted for existing NICE guidelines were updated where necessary. Other relevant guidelines were assessed for quality using the Appraisal of Guidelines Research and Evaluation (AGREE) instrument. The evidence base underlying high-quality existing guidelines was utilised and updated as appropriate.

Full details of the search strategies and filters used for the systematic review of clinical evidence are provided in Appendix H in the full guideline appendices.

Study Selection and Assessment of Methodological Quality

All primary-level studies included after the first scan of citations were acquired in full and re-evaluated for eligibility at the time they were being entered into the study information database. More specific eligibility criteria were developed for each review question and are described in the relevant clinical evidence chapters in the full version of the guideline. Eligible systematic reviews and primary-level studies were critically appraised for methodological quality (risk of bias) using a checklist (see The Guidelines Manual [NICE, 2012] for templates [see the "Availability of Companion Documents" field]). The eligibility of each study was confirmed by at least 1 member of the GDG.

For some review questions, it was necessary to prioritise the evidence with respect to the UK context (that is, external validity). To make this process explicit, the GDG took into account the following factors when assessing the evidence:

- Participant factors (for example, gender, age and ethnicity)
- Provider factors (for example, model fidelity, the conditions under which the intervention was performed and the availability of experienced staff to undertake the procedure)
- Cultural factors (for example, differences in standard care and differences in the welfare system)

It was the responsibility of the GDG to decide which prioritisation factors were relevant to each review question in light of the UK context.

Unpublished Evidence

Stakeholders were invited to submit any relevant unpublished data using the call for evidence process set out in the NICE manual (NICE, 2012). Additionally, authors and principal investigators were approached for unpublished evidence. The GDG used a number of criteria when deciding whether or not to accept unpublished data. First, the evidence must have been accompanied by a trial report containing sufficient detail to properly assess risk of bias. Second, the evidence must have been submitted with the understanding that data from the study and a summary of the study's characteristics would be published in the full guideline. Therefore, in most circumstances the GDG did not accept evidence submitted 'in confidence'. However, the GDG recognised that unpublished evidence submitted by investigators might later be retracted by those investigators if the inclusion of such data would jeopardise publication of their research.

Experience of Care

Reviews were sought of qualitative studies that used relevant first-hand experiences of service users and their families, partners or carers. A particular outcome was not specified by the GDG. Instead, the review was concerned with narrative data that highlighted the experience of care.

Health Economics Methods

Search Strategy for Economic Evidence

Scoping Searches

A broad preliminary search of the literature was undertaken in April 2013 to obtain an overview of the issues likely to be covered by the scope, and help define key areas. Searches were restricted to economic studies and HTA reports, and conducted in the following databases:

- EMBASE
- MEDLINE/MEDLINE In-Process
- HTA database (technology assessments)
- National Health Service Economic Evaluation Database (NHS EED)

Any relevant economic evidence arising from the clinical scoping searches was also made available to the health economist during the same period.

Systematic Literature Searches

After the scope was finalised, a systematic search strategy was developed to locate all the relevant evidence. The balance between sensitivity (the power to identify all studies on a particular topic) and specificity (the ability to exclude irrelevant studies from the results) was carefully considered, and a decision made to utilise a broad approach to searching to maximise retrieval of evidence to all parts of the guideline. Searches were restricted to economic studies and health technology assessment reports, and conducted in the following databases:

- EMBASE
- HTA database (technology assessments)
- MEDLINE/MEDLINE In-Process
- NHS EED
- PsycINFO

Any relevant economic evidence arising from the clinical searches was also made available to the health economist during the same period.

The search strategies were initially developed for MEDLINE before being translated for use in other databases/interfaces. Strategies were built up through a number of trial searches, and discussions of the results of the searches with the review team and GDG to ensure that all possible relevant search terms were covered. In order to assure comprehensive coverage, search terms for the guideline topic were kept purposely broad to help counter dissimilarities in database indexing practices and thesaurus terms, and imprecise reporting of study interventions by authors in the titles and abstracts of records.

For standard mainstream bibliographic databases (EMBASE, MEDLINE and PsycINFO) search terms for the guideline topic combined with a search filter for health economic studies. For searches generated in topic-specific databases (HTA, NHS EED) search terms for the guideline topic were used without a filter. The sensitivity of this approach was aimed at minimising the risk of overlooking relevant publications, due to potential weaknesses resulting from more focused search strategies. The search terms are set out in full in Appendix H in the full guideline appendices.

Reference Management

Citations from each search were downloaded into reference management software and duplicates removed. Records were then screened against the inclusion criteria of the reviews before being quality appraised. The unfiltered search results were saved and retained for future potential re-analysis to help keep the process both replicable and transparent.

Search Filters

The search filter for health economics is an adaptation of a pre-tested strategy designed by the Centre for Reviews and Dissemination (2007). The search filter is designed to retrieve records of economic evidence (including full and partial economic evaluations) from the vast amount of literature indexed to major medical databases such as MEDLINE. The filter, which comprises a combination of controlled vocabulary and free-text retrieval methods, maximises sensitivity (or recall) to ensure that as many potentially relevant records as possible are retrieved from a search. A full description of the filter is provided in Appendix H in the full version of the guideline.

Date and Language Restrictions

Systematic database searches were initially conducted in August 2013 up to the most recent searchable date. Search updates were generated on a 6-monthly basis, with the final re-runs carried out in October 2014. After this point, studies were included only if they were judged by the GDG to be exceptional (for example, the evidence was likely to change a recommendation).

Although no language restrictions were applied at the searching stage, foreign language papers were not requested or reviewed, unless they were of particular importance to an area under review. All the searches were restricted to research published from 1998 onwards in order to obtain data relevant to current healthcare settings and costs.

Other Search Methods

Other search methods involved scanning the reference lists of all eligible publications (systematic reviews, stakeholder evidence and included studies from the economic and clinical reviews) to identify further studies for consideration.

Full details of the search strategies and filter used for the systematic review of health economic evidence are provided in Appendix I in the full version of the guideline.

Inclusion Criteria for Economic Studies

The following inclusion criteria were applied to select studies identified by the economic searches for further consideration:

1. Only studies from Organisation for Economic Co-operation and Development countries were included, as the aim of the review was to identify economic information transferable to the UK context.
2. Selection criteria based on types of clinical conditions and service users as well as interventions assessed were identical to the clinical literature review.
3. Studies were included provided that sufficient details regarding methods and results were available to enable the methodological quality of the study to be assessed, and provided that the study's data and results were extractable. Poster presentations of abstracts were excluded.
4. Full economic evaluations that compared 2 or more relevant options and considered both costs and consequences as well as costing analyses that compared only costs between 2 or more interventions were included in the review.
5. Studies that adopted a very narrow perspective, ignoring major categories of costs to the NHS, were excluded; for example studies that estimated exclusively drug acquisition costs were considered non-informative to the guideline development process.

Number of Source Documents

Clinical Evidence Review

The number of publications retrieved in the literature search and that were included in the formulation of guideline recommendations is stated in the relevant chapter for each clinical question in the full version of the guideline (see the "Availability of Companion Documents" field).

Results of the Systematic Search of Economic Literature

The titles of all studies identified by the systematic search of the literature were screened for their relevance to the topic (that is, economic issues and information on health-related quality of life [HRQoL]). References that were clearly not relevant were excluded first. The abstracts of all potentially relevant studies (60 references) were then assessed against the inclusion criteria for economic evaluations by the health economist. Full texts of the studies potentially meeting the inclusion criteria (including those for which eligibility was not clear from the abstract) were obtained. Studies that did not meet the inclusion criteria, were duplicates, were secondary publications of 1 study, or had been updated in more recent publications were subsequently excluded. Economic evaluations eligible for inclusion (8 studies) were then appraised for their applicability and quality using the methodology checklist for economic evaluations. Finally, those studies that fully or partially met the applicability and quality criteria set by the National Institute for Health and Care Excellence (NICE) were considered at formulation of the guideline recommendations.

Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Overall Quality of Outcome Evidence in Grading of Recommendations Assessment, Development and Evaluation (GRADE)

Level	Description
High	Further research is very unlikely to change confidence in the estimate of effect.

Level	Description
Moderate	Further research is likely to have an important impact on confidence in the estimate of effect and may change the estimate.
Low	Further research is very likely to have an important impact on confidence in the estimate of effect and is likely to change the estimate.
Very Low	Any estimate of effect is very uncertain.

Methods Used to Analyze the Evidence

Meta-Analysis

Systematic Review with Evidence Tables

Description of the Methods Used to Analyze the Evidence

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Mental Health (NCCMH) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance.

Clinical Review Methods

Data Extraction

Quantitative Analysis

Study characteristics, aspects of methodological quality, and outcome data were extracted from all eligible studies, using Review Manager Version 5.3 and an Excel-based form (see Appendix K in the full version of the guideline [see the "Availability of Companion Documents" field]).

In most circumstances, for a given outcome (continuous and dichotomous), where more than 50% of the number randomised to any group were missing or incomplete, the study results were excluded from the analysis (except for the outcome 'leaving the study early', in which case, the denominator was the number randomised). Where there were limited data for a particular review, the 50% rule was not applied. In these circumstances the evidence was downgraded.

Where possible, outcome data from an intention-to-treat analysis (ITT) (that is, a 'once-randomised-always-analyse' basis) were used. Where ITT had not been used or there were missing data, the effect size for dichotomous outcomes were recalculated using worse-case scenarios. Where conclusions varied between scenarios, the evidence was downgraded.

Where some of the studies failed to report standard deviations (for a continuous outcome), and where an estimate of the variance could not be computed from other reported data or obtained from the study author, the following approach was taken. When the number of studies with missing standard deviations was less than one-third and when the total number of studies was at least 10, the pooled standard deviation was imputed (calculated from all the other studies in the same meta-analysis that used the same version of the outcome measure). In this case, the appropriateness of the imputation was made by comparing the standardised mean differences (SMDs) of those trials that had reported standard deviations against the hypothetical SMDs of the same trials based on the imputed standard deviations. If they converged, the meta-analytical results were considered to be reliable.

When the conditions above could not be met, standard deviations were taken from another related systematic review (if available). In this case, the results were considered to be less reliable.

The meta-analysis of survival data, such as time to any mood episode, was based on log hazard ratios and standard errors. Since individual participant data were not available in included studies, hazard ratios and standard errors calculated from a Cox proportional hazard model were extracted. Where necessary, standard errors were calculated from confidence intervals (CIs) or *p* value according to standard formulae. Data were summarised using the generic inverse variance method using Review Manager.

Consultation with another reviewer or members of the Guideline Development Group (GDG) was used to overcome difficulties with coding. Data from studies included in existing systematic reviews were extracted independently by 1 reviewer and cross-checked with the existing dataset. Where possible, 2 independent reviewers extracted data from new studies. Where double data extraction was not possible, data extracted by 1

reviewer was checked by the second reviewer. Disagreements were resolved through discussion. Where consensus could not be reached, a third reviewer or GDG members resolved the disagreement. Masked assessment (that is, blind to the journal from which the article comes, the authors, the institution and the magnitude of the effect) was not used since it is unclear that doing so reduces bias.

Single-Case and Small-n Studies

Single-case and small-n (SCSn) studies (which include 'N of 1 trials') make up a substantial part of the empirical evidence that is published in the field of learning disabilities. Unlike group-studies that present aggregated data for a group of participants that received either treatment or control, SCSn studies report outcomes for each participant separately. The approach uses a process of repeated observation during a certain period of time which allows for the assessment of change in targeted behaviours under different treatments of at least 1 independent variable. In the learning disability field, experimental designs typically follow an A-B-A-B reversal or multi-element format whilst quasi-experimental designs follow an A-B format. The primary strengths of the SCSn design are the analysis of behaviour of a single case, the assessment of both the process and product of change and the allowance of complex analysis in to the particular characteristics of 'responders' and 'non responders'. Limitations of the SCSn design (depending on the format used) include publication bias, carry-over and order effects, irreversibility and the generalisability of results. However, by aggregating the results from several SCSn studies in a meta-analysis generalisability becomes more feasible.

The frequent use of SCSn designs in the field of learning disabilities contrasts with the limited use of the randomised controlled trial (RCT) to evaluate treatment effects. Recruitment, ethical considerations and obtaining consent to randomisation have all contributed to a limitation of RCTs and other group comparison methods.

Evidence Synthesis

The method used to synthesise evidence depended on the review question and availability and type of evidence (see Appendix F in the full version of the guideline for full details). Briefly, for questions about the psychometric properties of instruments, reliability, validity and clinical utility were synthesised narratively based on accepted criteria. For questions about test accuracy, bivariate test accuracy meta-analysis was conducted where appropriate. For questions about the effectiveness of interventions, standard meta-analysis was used where appropriate, otherwise narrative methods were used with clinical advice from the GDG. In the absence of high-quality research, formal and informal consensus processes were used.

Grading the Quality of Evidence

For questions about the effectiveness of interventions, the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach was used to grade the quality of evidence from group comparisons for each outcome. Evidence from systematic reviews of SCSn designs was graded as 'low' or 'very low' quality without using the formal GRADE approach because specific methodology has not been developed to grade this type of evidence. For questions about the experience of care and the organisation and delivery of care, methodology checklists were used to assess the risk of bias, and this information was taken into account when interpreting the evidence. The technical team produced GRADE evidence profiles using GRADEprofiler (GRADEpro) software (Version 3.6), following advice set out in the GRADE handbook. All staff doing GRADE ratings were trained, and calibration exercises were used to improve reliability.

Evidence Profiles

A GRADE evidence profile was used to summarise both the quality of the evidence and the results of the evidence synthesis for each 'critical' and 'important' outcome (see Appendix O in the full version of the guideline for completed evidence profiles). The GRADE approach is based on a sequential assessment of the quality of evidence, followed by judgment about the balance between desirable and undesirable effects, and subsequent decision about the strength of a recommendation.

Within the GRADE approach to grading the quality of evidence, the following is used as a starting point:

- RCTs without important limitations provide high-quality evidence
- Observational studies without special strengths or important limitations provide low-quality evidence

For each outcome, quality may be reduced depending on 5 factors: limitations, inconsistency, indirectness, imprecision and publication bias. For the purposes of the guideline, each factor was evaluated using criteria provided in Table 6 in the full version of the guideline.

For observational studies without any reasons for down-grading, the quality may be up-graded if there is a large effect, all plausible confounding would reduce the demonstrated effect (or increase the effect if no effect was observed), or there is evidence of a dose-response gradient (details would be provided under the 'other' column).

Each evidence profile includes a summary of findings: number of participants included in each group, an estimate of the magnitude of the effect, and

the overall quality of the evidence for each outcome. Under the GRADE approach, the overall quality for each outcome is categorised into 1 of 4 groups (high, moderate, low, very low) (see the "Rating Scheme for the Strength of the Evidence" field).

Presenting Evidence to the Guideline Development Group

Study characteristics tables and, where appropriate, forest plots generated with Review Manager Version 5.2 and GRADE summary of findings tables (see below) were presented to the GDG.

Where meta-analysis was not appropriate and/or possible, the reported results from each primary-level study were reported in the study characteristics table and presented to the GDG. The range of effect estimates were included in the GRADE profile, and where appropriate, described narratively.

Summary of Findings Tables

Summary of findings tables generated from GRADEpro were used to summarise the evidence for each outcome and the quality of that evidence (see Table 7 in the full version of the guideline). The tables provide illustrative comparative risks, especially useful when the baseline risk varies for different groups within the population.

Extrapolation

When answering review questions, if there is no direct evidence from a primary dataset (defined as a data set which contains evidence on the population and intervention under review), based on the initial search for evidence, it may be appropriate to extrapolate from another data set. In this situation, the following principles were used to determine when to extrapolate:

- A primary dataset is absent, of low quality or is judged to be not relevant to the review question under consideration, and
- A review question is deemed by the GDG to be important, such that in the absence of direct evidence, other data sources should be considered, and
- Non-primary data source(s) is in the view of the GDG available, which may inform the review question

When the decision to extrapolate was made, the following principles were used to inform the choice of the non-primary dataset:

- The populations (usually in relation to the specified diagnosis or problem which characterises the population) under consideration share some common characteristic but differ in other ways, such as age, gender or in the nature of the disorder (for example, a common behavioural problem; acute versus chronic presentations of the same disorder), and
- The interventions under consideration in the view of the GDG have one or more of the following characteristics:
    - Share a common mode of action (for example, the pharmacodynamics of drug; a common psychological model of change—operant conditioning)
    - Be feasible to deliver in both populations (for example, in terms of the required skills or the demands of the healthcare system)
    - Share common side effects/harms in both populations, and
- The context or comparator involved in the evaluation of the different datasets shares some common elements which support extrapolation, and
- The outcomes involved in the evaluation of the different datasets shares some common elements which support extrapolation (for example, improved mood or a reduction in behavior that challenges).

When the choice of the non-primary dataset was made, the following principles were used to guide the application of extrapolation:

- The GDG should first consider the need for extrapolation through a review of the relevant primary dataset and be guided in these decisions by the principles for the use of extrapolation.
- In all areas of extrapolation datasets should be assessed against the principles for determining the choice of datasets. In general the criteria in the four principles set out above for determining the choice should be met.
- In deciding on the use of extrapolation, the GDG will have to determine if the extrapolation can be held to be reasonable, including ensuring that:
    - The reasoning behind the decision can be justified by the clinical need for a recommendation to be made
    - The absence of other more direct evidence, and by the relevance of the potential dataset to the review question can be established
    - The reasoning and the method adopted is clearly set out in the relevant section of the guideline

Health Economics Methods

The aim of the health economics was to contribute to the guideline's development by providing evidence on the cost effectiveness of interventions

for people with a learning disability and behaviour that challenges covered in the guideline. This was achieved by:

- Systematic literature review of existing economic evidence
- Decision-analytic economic modelling

Systematic reviews of economic literature were conducted in all areas covered in the guideline. Economic modelling was undertaken in areas with likely major resource implications, where the current extent of uncertainty over cost effectiveness was significant and economic analysis was expected to reduce this uncertainty, in accordance with The Guidelines Manual (NICE, 2012; see the "Availability of Companion Documents" field). Prioritisation of areas for economic modelling was a joint decision between the Health Economist and the GDG. The rationale for prioritising review questions for economic modelling was set out in an economic plan agreed between NICE, the GDG, the Health Economist and the other members of the technical team. The following economic questions were selected as key issues that were addressed by economic modelling:

- Parent training for the management of behaviour that challenges in children and young people with a learning disability
- Psychological and pharmacological interventions for the management of sleep problems in children and young people with a learning disability
- The use of antipsychotics for the management of behaviour that challenges in children and young people with a learning disability

In addition, literature on the health-related quality of life (HRQoL) of people with a learning disability and behaviour that challenges was systematically searched to identify studies reporting appropriate utility scores that could be utilised in a cost-utility analysis.

Methods employed in economic modelling are described in the relevant economic sections of the evidence chapters in the full version of the guideline.

Applicability and Quality Criteria for Economic Studies

All economic papers eligible for inclusion were appraised for their applicability and quality using the methodology checklist for economic evaluations recommended by NICE (NICE, 2012). The methodology checklist for economic evaluations was also applied to the economic models developed specifically for this guideline. All studies that fully or partially met the applicability and quality criteria described in the methodology checklist were considered during the guideline development process, along with the results of the economic modelling conducted specifically for this guideline. The completed methodology checklists for all economic evaluations considered in the guideline are provided in Appendix R of the full version of the guideline.

Methods Used to Formulate the Recommendations

Expert Consensus (Nominal Group Technique)

Informal Consensus

Description of Methods Used to Formulate the Recommendations

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Mental Health (NCCMH) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance.

The Guideline Development Group

During the consultation phase, members of the Guideline Development Group (GDG) were appointed by an open recruitment process. GDG membership consisted of: professionals in psychiatry, clinical psychology, nursing, social work, speech and language therapy, and general practice; academic experts in psychiatry and psychology; commissioning managers; and carers and representatives from service user and carer organisations. The guideline development process was supported by staff from the NCCMH, who undertook the clinical and health economic literature searches, reviewed and presented the evidence to the GDG, managed the process, and contributed to drafting the guideline.

Guideline Development Group Meetings

Eleven GDG meetings were held between July 2013 and February 2015. During each day-long GDG meeting, in a plenary session, review questions and clinical and economic evidence were reviewed and assessed, and recommendations formulated. At each meeting, all GDG members declared any potential conflicts of interest (see Appendix B in the full guideline appendices), and service user and carer concerns were routinely

discussed as a standing agenda item.

Service Users and Carers

Individuals with direct experience of services gave an integral service-user focus to the GDG and the guideline. The GDG included carers and a representative of a national service user group. They contributed as full GDG members to writing the review questions, providing advice on outcomes most relevant to service users and carers, helping to ensure that the evidence addressed their views and preferences, highlighting sensitive issues and terminology relevant to the guideline, and bringing service user research to the attention of the GDG. In drafting the guideline, they met with the NCCMH team on several occasions to develop the chapter on experience of care and they contributed to writing the guideline's introduction and identified recommendations from the service user and carer perspective.

Expert Advisers

Expert advisers, who had specific expertise in 1 or more aspects of treatment and management relevant to the guideline, assisted the GDG, commenting on specific aspects of the developing guideline and making presentations to the GDG.

National and International Experts

National and international experts in the area under review were identified through the literature search and through the experience of the GDG members. These experts were contacted to identify unpublished or soon-to-be published studies, to ensure that up-to-date evidence was included in the development of the guideline. They informed the GDG about completed trials at the pre-publication stage, systematic reviews in the process of being published, studies relating to the cost effectiveness of treatment and trial data if the GDG could be provided with full access to the complete trial report.

Review Protocols

Review questions drafted during the scoping phase were discussed by the GDG at the first few meetings and amended as necessary. The review questions were used as the starting point for developing review protocols for each systematic review (described in more detail below). Where appropriate, the review questions were refined once the evidence had been searched and, where necessary, subquestions were generated. The final list of review questions can be found in Appendix F in the full guideline appendices.

For questions about interventions, the PICO (Population, Intervention, Comparison and Outcome) framework was used to structure each question (see Table 3 in the full version of the guideline).

Questions relating to case identification and assessment tools and methods do not involve an intervention designed to treat a particular condition, and therefore the PICO framework was not used. Rather, the questions were designed to pick up key issues specifically relevant to clinical utility, for example their accuracy, reliability, safety and acceptability to the service user.

In some situations, the prognosis of a particular condition is of fundamental importance, over and above its general significance in relation to specific interventions. Areas where this is particularly likely to occur relate to assessment of risk, for example in terms of behaviour modification or screening and early intervention. In addition, review questions related to issues of service delivery are occasionally specified in the remit from the Department of Health. In these cases, appropriate review questions were developed to be clear and concise.

Where review questions about service user experience were specified in the scope, the SPICE (Setting, Perspective, Intervention, Comparison, Evaluation) format was used to structure the questions (see Table 4 in the full guideline appendices).

To help facilitate the literature review, a note was made of the best study design type to answer each question. There are 4 main types of review question of relevance to NICE guidelines. These are listed in Table 5 in the full version of the guideline. For each type of question, the best primary study design varies, where 'best' is interpreted as 'least likely to give misleading answers to the question'. For questions about the effectiveness of interventions, where randomised controlled trials (RCTs) were not available, the review of other types of evidence was pursued only if there was reason to believe that it would help the GDG to formulate a recommendation. However, in all cases, a well-conducted systematic review (of the appropriate type of study) is likely to always yield a better answer than a single study.

Using NICE Evidence Reviews and Recommendations from Existing Guidelines

When review questions overlap and evidence from another guideline applies to a question in the current guideline, it might be desirable and practical to incorporate or adapt recommendations published in NICE guidelines. Adaptation refers to the process by which an existing recommendation is modified in order to facilitate its placement in a new guideline. Incorporation refers to the placement of a recommendation that was developed for another guideline into a new guideline, with no material changes to wording or structure. Incorporation would be used in relatively rare circumstances, as cross-referring to the other guideline will often be all that is necessary.

Incorporation or adaptation is likely to be substantially more complex where health economics were a major part of the decision making. In these circumstances, these methods are only used rarely after full and detailed consideration. Refer to Section 3.7 in the full version of the guideline for the criteria used for incorporation and adaptation in this guideline.

In deciding whether to choose between incorporation or adaptation of existing guideline recommendations, the GDG considered whether the direct evidence obtained from the current guideline dataset was of sufficient quality to allow development of recommendations. It was only where (a) such evidence was not available or insufficient to draw robust conclusions and (b) where methods used in other NICE guidelines were sufficiently robust that the 'incorporate and adapt' method could be used. Recommendations were only incorporated or adapted after the GDG had reviewed evidence supporting previous recommendations and confirmed that they agreed with the original recommendations.

When adaptation is used, the meaning and intent of the original recommendation is preserved but the wording and structure of the recommendation may change. Preservation of the original meaning (that is, that the recommendation faithfully represents the assessment and interpretation of the evidence contained in the original guideline document evidence reviews) and intent (that is, the intended action[s] specified in the original recommendation will be achieved) is an essential element of the process of adaptation.

Roles and Responsibilities

The guideline review team, in consultation with the guideline Facilitator and Chair, were responsible for identifying overlapping questions and deciding if it would be appropriate to incorporate or to adapt following the principles above. For adapted recommendations, at least 2 members of the GDG for the original guideline were consulted to ensure the meaning and intent of the original recommendation was preserved. The GDG confirmed the process had been followed, that there was insufficient evidence to make new recommendations, and agreed all adaptations to existing recommendations.

In evidence chapters of the full version of the guideline where incorporation and adaptation have been used, the original review questions are listed with the rationale for the judgement on the similarity of questions. Tables are then provided that set out the original recommendation, a brief summary of the original evidence, the new recommendation, and the reasons for adaptation. For an adapted recommendation, details of any contextual information are provided, along with information about how the GDG ensured that the meaning and intent of the adapted recommendation was preserved.

Drafting of Adapted Recommendations

The drafting of adapted recommendations conformed to standard NICE procedures for the drafting of guideline recommendations, preserved the original meaning and intent, and aimed to minimise the degree or re-writing and re-structuring.

From Evidence to Recommendations

Once the clinical and health economic evidence was summarised, the GDG drafted the recommendations. In making recommendations, the GDG took into account the trade-off between the benefits and harms of the intervention/instrument, as well as other important factors, such as the trade-off between net health benefits and resource use, values of the GDG and society, the requirements to prevent discrimination and to promote equality, and the GDG's awareness of practical issues.

Finally, to show clearly how the GDG moved from the evidence to the recommendations, each chapter (or subsection) of the full version of the guideline has a section called 'recommendations and link to evidence'. Underpinning this section is the concept of the 'strength' of a recommendation. This takes into account the quality of the evidence but is conceptually different. Some recommendations are "strong" in that the GDG believes that the vast majority of healthcare professionals and service users would choose a particular intervention if they considered the evidence in the same way that the GDG has. This is generally the case if the benefits clearly outweigh the harms for most people and the intervention is likely to be cost effective. However, there is often a closer balance between benefits and harms, and some service users would not choose an intervention whereas others would. This may happen, for example, if some service users are particularly averse to some side effect and others are not.

In these circumstances the recommendation is generally weaker, although it may be possible to make stronger recommendations about specific groups of service users. The strength of each recommendation is reflected in the wording of the recommendation, rather than by using ratings, labels or symbols.

Where the GDG identified areas in which there are uncertainties or where robust evidence was lacking, they developed research recommendations. Those that were identified as 'high priority' were developed further in the short version of the guideline, and presented in Appendix G in the full guideline appendices.

Method Used to Answer a Review Question in the Absence of Appropriately Designed, High-Quality Research

In the absence of appropriately designed, high-quality research (including indirect evidence where it would be appropriate to use extrapolation), both formal and informal consensus processes were adopted. Refer to Sections 3.5.8.1 and 3.5.8.2 in the full version of the guideline for descriptions of the formal and informal consensus methods.

Rating Scheme for the Strength of the Recommendations

Strength of Recommendations

Some recommendations can be made with more certainty than others. The Guideline Development Group (GDG) makes a recommendation based on the trade-off between the benefits and harms of an intervention, taking into account the quality of the underpinning evidence. For some interventions, the GDG is confident that, given the information it has looked at, most people would choose the intervention. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the strength of the recommendation).

Interventions That Must (or Must Not) Be Used

The GDG usually uses 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally 'must' (or 'must not') is used if the consequences of not following the recommendation could be extremely serious or potentially life threatening.

Interventions That Should (or Should Not) Be Used – a 'Strong' Recommendation

The GDG uses 'offer' (and similar words such as 'refer' or 'advise') when confident that, for the vast majority of people, an intervention will do more good than harm, and be cost effective. The GDG uses similar forms of words (for example, 'Do not offer…') when they are confident that an intervention will not be of benefit for most people.

Interventions That Could Be Used

The GDG uses 'consider' when confident that an intervention will do more good than harm for most people, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to have the intervention at all, is more likely to depend on the person's values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the person.

Cost Analysis

Presentation of Economic Evidence

The economic evidence considered in the guideline is provided in the respective evidence chapters, following presentation of the relevant clinical evidence. The references to included studies and the respective evidence tables with the study characteristics and results are provided in Appendix S in the full guideline appendices (see the "Availability of Companion Documents" field). Methods and results of economic modelling undertaken alongside the guideline development process are presented in the relevant evidence chapters. Characteristics and results of all economic studies considered during the guideline development process (including modelling studies conducted for this guideline) are summarised in economic evidence profiles accompanying respective Grading of Recommendations Assessment, Development and Evaluation (GRADE) clinical evidence profiles in Appendix T in the full guideline appendices.

Method of Guideline Validation

External Peer Review

Internal Peer Review

Description of Method of Guideline Validation

Validation of the Guideline

Registered stakeholders had an opportunity to comment on the draft guideline, which was posted on the National Institute for Health and Care Excellence (NICE) website during the consultation period. Following the consultation, all comments from stakeholders and experts (see Appendix D in the full guideline appendices [see the "Availability of Companion Documents" field]) were responded to, and the guideline updated as

appropriate. NICE also reviewed the guideline and checked that stakeholders' comments had been addressed.

Following the consultation period, the Guideline Development Group (GDG) finalised the recommendations and the National Collaborating Centre for Mental Health (NCCMH) produced the final documents. These were then submitted to NICE for a quality assurance check. Any errors were corrected by the NCCMH, then the guideline was formally approved by NICE and issued as guidance to the National Health Service (NHS) in England.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of evidence supporting the recommendations is not specifically stated.

The type and quality of evidence supporting each review question are described in evidence profiles in the full version of the guideline (see the "Availability of Companion Documents" field).

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

- The evidence suggested that training staff may have benefits in terms of reduced behaviour that challenges and improved fidelity of treatment through improved staff skills.
- The evidence suggested that educational interventions in preschool children have benefits in terms of behaviour that challenges and adaptive functioning. The Guideline Development Group (GDG) was of the view that these interventions with young children at risk of developing behaviour that challenges may also have long-term benefits in supporting their integration into mainstream education.
- The GDG recognised the potential value of early interventions because they equip parents to better manage behaviour so that they may not develop into long-term problems resulting in greater burden for the person, the family and the wider service system.

Refer to the "Trade-off between clinical benefits and harms" sections in the full version of the guideline (see the "Availability of Companion Documents" field) for benefits of specific interventions.

Potential Harms

- There was evidence of harms from medication including weight gain, raised prolactin levels and sedation; data on other potential long-term harms were absent. The evidence for the use of antipsychotic medication for children was of better quality than that for adults but the concerns about potential harms (for example, raised prolactin levels) were also higher.
- The Guideline Development Group (GDG) was aware of the possible harms that could arise from the use of restrictive interventions, which include the loss of liberty and possible physical harms that might arise from manual or mechanical restraint. Reporting of harms was limited in the studies included in the systematic review.

Refer to the "Trade-off between clinical benefits and harms" sections in the full version of the guideline (see the "Availability of Companion Documents" field) for additional discussion of harms of specific interventions.

Qualifying Statements

Qualifying Statements

- This guidance represents the view of the National Institute for Health and Care Excellence (NICE), which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate

to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summaries of product characteristics of any drugs.

- Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.
- The guideline will assume that prescribers will use a medication's summary of product characteristics to inform decisions made with people offered medication (or their family members or carers, as appropriate).
- This guideline recommends some medications for indications for which they do not have a UK marketing authorisation at the date of publication, if there is good evidence to support that use.
- The prescriber should follow relevant professional guidance, taking full responsibility for the decision. The person offered the medication (or those with authority to give consent on their behalf) should provide informed consent, which should be documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information. Where recommendations have been made for the use of medicines outside their licensed indications ('off-label use'), these medicines are marked with a footnote in the recommendations.
- See the "Person-centred care" section in the original guideline document for information about individual needs and preferences and transition of care.
- For all recommendations, NICE expects that there is discussion with the person about the risks and benefits of the interventions, and their values and preferences. This discussion aims to help them to reach a fully informed decision (see also person-centred care in the original guideline document).
- See the original guideline document for information about safeguarding adults and children.

Implementation of the Guideline

Description of Implementation Strategy

Key Priorities for Implementation

The following recommendations have been identified as priorities for implementation.

General Principles of Care

Working with People with a Learning Disability and Behaviour That Challenges, and Their Families and Carers

When providing support and interventions for people with a learning disability and behaviour that challenges, and their family members or carers:

- Take into account the severity of the person's learning disability, their developmental stage, and any communication difficulties or physical or mental health problems
- Aim to provide support and interventions:
  - In the least restrictive setting, such as the person's home, or as close to their home as possible, and
  - In other places where the person regularly spends time (for example, school or residential care)
- Aim to prevent, reduce or stop the development of future episodes of behaviour that challenges
- Aim to improve quality of life
- Offer support and interventions respectfully
- Ensure that the focus is on improving the person's support and increasing their skills rather than changing the person
- Ensure that they know who to contact if they are concerned about care or interventions, including the right to a second opinion
- Offer independent advocacy to the person and to their family members or carers

Delivering Effective Care

If initial assessment and management have not been effective, or the person has more complex needs, health and social care provider organisations should ensure that teams providing care have prompt and coordinated access to specialist assessment, support and intervention services. These services should provide advice, supervision and training from a range of staff to support the implementation of any care or intervention, including psychologists, psychiatrists, behavioural analysts, nurses, social care staff, speech and language therapists, educational staff, occupational therapists, physiotherapists, physicians, paediatricians and pharmacists.

Support and Interventions for Family Members or Carers

When providing support to family members or carers (including siblings):

- Recognise the impact of living with or caring for a person with a learning disability and behaviour that challenges
- Explain how to access family advocacy
- Consider family support and information groups if there is a risk of behaviour that challenges, or it is emerging
- Consider formal support through disability-specific support groups for family members or carers and regular assessment of the extent and severity of the behaviour that challenges
- Provide skills training and emotional support, or information about these, to help them take part in and support interventions for the person with a learning disability and behaviour that challenges

Early Identification of the Emergence of Behaviour That Challenges

Everyone involved in caring for and supporting children, young people and adults with a learning disability (including family members and carers) should understand the risk of behaviour that challenges and that it often develops gradually. Pay attention to and record factors that may increase this risk, including:

- Personal factors, such as:
  - A severe learning disability
  - Autism
  - Dementia
  - Communication difficulties (expressive and receptive)
  - Visual impairment (which may lead to increased self-injury and stereotypy)
  - Physical health problems
  - Variations with age (peaking in the teens and twenties)
- Environmental factors, such as:
  - Abusive or restrictive social environments
  - Environments with little or too much sensory stimulation and those with low engagement levels (for example, little interaction with staff)
  - Developmentally inappropriate environments (for example, a curriculum that makes too many demands on a child or young person)
  - Environments where disrespectful social relationships and poor communication are typical or where staff do not have the capacity or resources to respond to people's needs
  - Changes to the person's environment (for example, significant staff changes or moving to a new care setting)

Assessment of Behaviour That Challenges

The Assessment Process

When assessing behaviour that challenges ensure that:

- The person being assessed remains at the centre of concern and is supported throughout the process
- The person and their family members and carers are fully involved in the assessment process
- The complexity and duration of the assessment process is proportionate to the severity, impact, frequency and duration of the behaviour
- Everyone involved in delivering assessments understands the criteria for moving to more complex and intensive assessment
- All current and past personal and environmental factors (including care and educational settings) that may lead to behaviour that challenges are taken into account
- Assessment is a flexible and continuing (rather than a fixed) process, because factors that trigger and maintain behaviour may change over time
- Assessments are reviewed after any significant change in behaviour
- Assessments are focused on the outcomes of reducing behaviour that challenges and improving quality of life
- The resilience, resources and skills of family members and carers are taken into account
- The capacity, sustainability and commitment of the staff delivering the behaviour support plan are taken into account

Risk Assessment

Assess and regularly review the following areas of risk during any assessment of behaviour that challenges:

- Suicidal ideation, self-harm (in particular in people with depression) and self-injury
- Harm to others
- Self-neglect
- Breakdown of family or residential support
- Exploitation, abuse or neglect by others
- Rapid escalation of the behaviour that challenges.

Ensure that the behaviour support plan includes risk management.

Functional Assessment of Behaviour

Vary the complexity and intensity of the functional assessment according to the complexity and intensity of behaviour that challenges, following a phased approach as set out below.

- Carry out pre-assessment data gathering to help shape the focus and level of the assessment.
- For recent-onset behaviour that challenges, consider brief structured assessments such as the Functional Analysis Screening Tool or Motivation Assessment Scale to identify relationships between the behaviour and what triggers and reinforces it.
- For recent-onset behaviour that challenges, or marked changes in patterns of existing behaviours, take into account whether any significant alterations to the person's environment and physical or psychological health are associated with the development or maintenance of the behaviour.
- Consider in-depth assessment involving interviews with family members, carers and others, direct observations, structured record keeping, questionnaires and reviews of case records.
- If a mental health problem may underlie behaviour that challenges, consider initial screening using assessment scales such as the Diagnostic Assessment Schedule for the Severely Handicapped-II, Psychiatric Assessment Schedule for Adults with a Developmental Disability or the Psychopathology Instrument for Mentally Retarded Adults and seek expert opinion.

Psychological and Environmental Interventions

Interventions for Behaviour That Challenges

Consider personalised interventions for children, young people and adults that are based on behavioural principles and a functional assessment of behaviour, tailored to the range of settings in which they spend time, and consist of:

- Clear targeted behaviours with agreed outcomes
- Assessment and modification of environmental factors that could trigger or maintain the behaviour (for example, altering task demands for avoidant behaviours)
- Addressing staff and family member or carer responses to behaviour that challenges
- A clear schedule of reinforcement of desired behaviour and the capacity to offer reinforcement promptly
- A specified timescale to meet intervention goals (modifying intervention strategies that do not lead to change within a specified time)

Medication

Consider antipsychotic medication to manage behaviour that challenges only if:

- Psychological or other interventions alone do not produce change within an agreed time or
- Treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or
- The risk to the person or others is very severe (for example, because of violence, aggression or self-injury)

Only offer antipsychotic medication in combination with psychological or other interventions.

Implementation Tools

Clinical Algorithm

Foreign Language Translations

Mobile Device Resources

Patient Resources

Resources

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

Living with Illness

Staying Healthy

IOM Domain

Effectiveness

Identifying Information and Availability

Bibliographic Source(s)

National Collaborating Centre for Mental Health. Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. London (UK): National Institute for Health and Care Excellence (NICE); 2015 May 28. 57 p. (NICE guideline; no. 11).

Adaptation

The Guideline Development Group (GDG) adapted recommendations from "Common mental health disorders: Identification and pathways to care" where appropriate:

- NICE. Common mental health disorders: Identification and pathways to care. NICE clinical guideline 123. 2011. Available from: http://www.nice.org.uk/guidance/cg123 .

Date Released

2015 May 28

Guideline Developer(s)

National Collaborating Centre for Mental Health - National Government Agency [Non-U.S.]

Source(s) of Funding

National Institute for Health and Care Excellence (NICE)

Guideline Committee

Guideline Development Group

Composition of Group That Authored the Guideline

Guideline Development Group: Glynis Murphy (*Chair*), Professor of Clinical Psychology and Disability, University of Kent, Co-Director, Tizard Centre, University of Kent; David Allen, Clinical Director, Positive Response Training and Consultancy, Professor, Tizard Centre, University of Kent; David Branford, Chief Pharmacist, Derbyshire Healthcare Foundation NHS Trust (retired); Alick Bush, Lead Psychologist, St Andrew's Healthcare; Carole Buckley, GP, The Old School Surgery, Bristol; Vivien Cooper, Carer representative and Chief Executive Officer, The Challenging Behaviour Foundation; Jo Dwyer, Clinical Specialist Occupational Therapist, Lewisham Team for Adults with Learning Disabilities, Guy's and St Thomas' NHS Foundation Trust; Angela Hassiotis, Professor, University College London and Honorary Consultant Psychiatrist, Camden and Islington Foundation Trust; Phil Howell, Physical Interventions Accreditation Scheme Manager and Positive Behaviour Support Consultant, British Institute of Learning Disabilities; Simon Jones, Head of Behavioural Support, Care UK; Richard Mills, Research Director, Research Autism; David Newton, Team Manager, Adult Safeguarding Quality Assurance Team, Adult Social Care Directorate, Nottingham City Council; Steve Noone, Consultant Clinical Psychologist, Northumberland, Tyne and Wear Foundation NHS Trust; Phil Perkins, Senior Community Learning Disability Nurse for Children and Young People, Surrey and Borders Partnership NHS Foundation Trust; Victoria Slonims, Senior Consultant Speech and Language Therapist, and Honorary Senior Lecturer, Evelina Children's Hospital, Guy's and St Thomas' NHS Foundation Trust; Keith Wyncoll, Carer representative

Financial Disclosures/Conflicts of Interest

- With a range of practical experience relevant to behaviour that challenges in people with learning disabilities in the Guideline Development Group (GDG), members were appointed because of their understanding and expertise in healthcare for people with behaviour that challenges in people with learning disabilities and support for their families and carers, including: scientific issues; health research; the delivery and receipt of healthcare, along with the work of the healthcare industry; and the role of professional organisations and organisations for people with learning disabilities and behaviour that challenges and their families and carers.
- To minimise and manage any potential conflicts of interest, and to avoid any public concern that commercial or other financial interests have affected the work of the GDG and influenced guidance, members of the GDG must declare as a matter of public record any interests held by themselves or their families which fall under specified categories. These categories include any relationships they have with the healthcare industries, professional organisations and organisations for people with learning disabilities and behaviour that challenges and their families/carers.
- Individuals invited to join the GDG were asked to declare their interests before being appointed. To allow the management of any potential conflicts of interest that might arise during the development of the guideline, GDG members were also asked to declare their interests at each GDG meeting throughout the guideline development process. The interests of all the members of the GDG are listed below, including interests declared prior to appointment and during the guideline development process.
- Please note that the Challenging Behaviour and Learning Disabilities Guideline Development Group was recruited under NICE's 2007 declaration of interests policy.
- See Section 4.4 in the original guideline document for a list of declarations (see the "Availability of Companion Documents" field).

Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Guideline Availability

Electronic copies: Available from the National Institute for Health and Care Excellence (NICE) Web site . Also available for download in ePub and eBook formats from the NICE Web site .

Availability of Companion Documents

The following are available:

- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. Full guideline. London (UK): National Institute for Health and Care Excellence; 2015 May. 371 p. (NICE guideline; no. 11). Electronic copies: Available from the National Institute for Health and Care Excellence (NICE) Web site .
- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. Appendices. London (UK): National Institute for Health and Care Excellence; 2015 May. (NICE guideline; no. 11). Electronic copies: Available from the NICE Web site .
- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. Baseline assessment tool. London (UK): National Institute for Health and Care Excellence; 2015 May. (NICE guideline; no. 11). Electronic copies: Available from the NICE Web site .
- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. Costing statement. London (UK): National Institute for Health and Care Excellence; 2015 May. 14 p. (NICE guideline; no. 11). Electronic copies: Available from the NICE Web site .
- The guidelines manual 2012. London (UK): National Institute for Health and Care Excellence (NICE); 2012 Nov. Electronic copies: Available from the NICE Web site .

Patient Resources

The following is available:

- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. Information for the public. London (UK): National Institute for Health and Care Excellence (NICE); 2015 May. 13 p. Available from the National Institute for Health and Care Excellence (NICE) Web site . Also available for download in eBook and ePub formats from the NICE Web site . Also available in Welsh from the NICE Web site .

Please note: This patient information is intended to provide health professionals with information to share with their patients to help them better understand their health and their diagnosed disorders. By providing access to this patient information, it is not the intention of NGC to provide specific medical advice for particular patients. Rather we urge patients and their representatives to review this material and then to consult with a licensed health professional for evaluation of treatment options suitable for them as well as for diagnosis and answers to their personal medical questions. This patient information has been derived and prepared from a guideline for health care professionals included on NGC by the authors or publishers of that original guideline. The patient information is not reviewed by NGC to establish whether or not it accurately reflects the original guideline's content.

NGC Status

This NGC summary was completed by ECRI Institute on July 28, 2015. This summary was updated by ECRI Institute on May 24, 2016 following the U.S. Food and Drug Administration advisory on Olanzapine.

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